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ABSTRACT

This is one in a series of reports to the President and Congress developed by the President's Information Technology Advisory Committee (PITAC) on key contemporary issues in information technology. This report argues that significant improvements in health care would be possible if modern clinical information systems were widely implemented and a sound national health information infrastructure were in place. Challenges to realizing the vision of new technologies providing opportunities for improving health care are discussed in terms of six findings: lack of an accepted national vision; critical long-term issues not addressed; decision-support systems needed; too few bioinformatics professionals; reliance on outside innovations; and Department of Health and Human Services issues. These findings are followed by six recommendations: establish pilot projects and Enabling Technology Centers to extend practical uses of information technology to health care systems and biomedical research; NIH, in close collaboration with other agencies, should design and deploy a scalable national computing and information infrastructure to support the biomedical research community; congress should enhance existing privacy rules by enacting legislation that assures sound practices for managing personally identifiable health information of any kind; establish programs to increase the pool of biomedical research and health care professionals with training at the intersection of health and information technology; the Data Council of the Department of Health and Human Services (DHHS) should outline its vision for using information technology to improve health care in this country and subsequently devote the necessary resources to do the basic information technology research critical to accomplishing these goals in the long term; and DHHS should appoint a senior information technology leader to provide strategic leadership across DHHS and focus on the importance of information technology in addressing problems in health care. (AEF)

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REPORT TO THE PRESIDENT

ED 462 968

Transforming Health Care Through Information Technology

President's Information Technology Advisory Committee

Panel on Transforming Health Care

February 2001

IR021128

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Illustration notes

Thanks to James J. Caras, National Science Foundation designer-illustrator, for the cover illustration.

The graphic accompanying this report's text is a schematic of the clockwise-twisted structure of deoxyribonucleic acid (DNA) – the hereditary substance in cells that carries the coded instructions for shaping all forms of life. The graphic indicates the chemical pairs that make up this universal genetic code: adenine (A), which always pairs with thymine (T), and guanine (G), which pairs with cytosine (C). The successful sequencing and mapping announced in February 2001 of most of the approximately three billion DNA "letters" in the estimated 30,000-35,000 genes of the human genetic blueprint were accelerated by many years through the use of advanced information technologies. Scientists working in the Human Genome Project public consortium and in related private efforts relied on high-end computational platforms and specialized software to analyze huge quantities of genetic data in a tiny fraction of the time that calculations by hand would have required. The worldwide scientific effort was also speeded because large-scale genetic databases representing pieces of the enormous biological puzzle could be stored and shared over the Internet.

These advanced technologies will also enable researchers to move rapidly ahead now with studies of the relationships between genetic structures and human diseases.

REPORT TO THE PRESIDENT

Transforming Health Care Through Information Technology

PRESIDENT'S INFORMATION TECHNOLOGY ADVISORY COMMITTEE

Panel on Transforming Health Care

GATC CTAG

February 2001

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Larry Smarr
Joe F. Thompson
Leslie Vadasz
Steven J. Wallach

February 9, 2001

The Honorable George W. Bush
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

During the past year, the President's Information Technology Advisory Committee (PITAC) has focused much of its attention on providing a vision for information technology's role in helping to drive progress in the 21st century. As part of this effort, we established several panels to examine specific issues, including a panel to review the ways in which information technology can transform health care and increase access to care for all citizens. The Federal government has a critical role to play in driving this progress, which PITAC has outlined in our report enclosed with this letter, ***Transforming Health Care Through Information Technology***.

Information technology provides many exciting applications for the health sector, such as computer-aided surgery, the use of telesensing methods to examine patients from their homes, and patient/doctor interaction via the Internet and digital medical libraries. Information technology tools can provide the health care sector with unprecedented productivity and quality of care if there is a strategic vision and adequate research to ensure success. **However, PITAC found that at present the U.S. lacks a broadly disseminated and accepted national vision for information technology in health care.** In addition, the biomedical community, including the Federal agencies, is not focused on the basic, long-term information technology research required to provide the community with the state of the art tools necessary to take full advantage of the Information Age.

In order to rectify this situation, PITAC strongly recommends that the Department of Health and Human Services (DHHS) outline its vision for using information technology to improve health care in this country and devote the necessary resources to do the basic information technology research critical to accomplishing these goals in the long term. Further, DHHS should appoint a senior information technology leader to provide strategic leadership across DHHS and focus on the importance of information technology in addressing pressing problems in health care. We further recommend four ways that the information technology/health care nexus can be Accomplished:

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- First, pilot projects and Enabling Technology Centers should be established to extend the practical uses of information technology to health care systems and biomedical research;
- Second, a scalable national computing infrastructure should be provided to support the biomedical research community;
- Third, Congress should enact legislation that assures sound practices for managing personally identifiable health information of any kind; and
- And fourth, programs should be established to increase the pool of biomedical research and health care professionals with training at the intersection of health and information technology.

We hope that these recommendations will represent a major step toward realizing the potential of information technology to increase every American's access to quality health care. PITAC looks forward to working with you, your Administration, and members of Congress to help dramatically improve our health care system through the use of information technology tools. As PITAC strives to provide sound, well-researched advice, we hope that you and members of your Administration will feel free at any time to discuss these and other important issues with members of the committee.

Sincerely,

Raj Reddy
Co-chair

Irving Wladawsky-Berger
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Enclosure

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About This Report

"Transforming Health Care Through Information Technology" is one in a series of reports to the President and Congress developed by the President's Information Technology Advisory Committee (PITAC) on key contemporary issues in information technology. These focused reports examine specific aspects of the near- and long-term research and development and policies we need to capture the potential of information technology to help grow our economy and address important problems facing the Nation.

The 24-member PITAC, comprising corporate and academic leaders, was established by Executive Order of the President in 1997 and renewed for a two-year term in 1999. Its charge is to provide the Federal government with expert independent guidance on maintaining America's preeminence in high performance computing and communications, information technology, and Next Generation Internet R&D.

In February 1999, the PITAC issued an overview and analysis of the current state of Federal information technology research and development in a report entitled "Information Technology Research: Investing in Our Future." That report set forth a vision of how information technology can transform the way we live, learn, work, and play, with resulting benefits for all Americans. But the report warned that Federal information technology research and development is seriously inadequate, given its economic, strategic, and societal importance. The Committee concluded that the Government is funding only a fraction of the research needed to maintain U.S. preeminence in information technology and propel the positive transformations it enables.

The Committee identified 10 information technology "National Challenge Transformations" that are critical to America's future. To meet these transformation challenges, the PITAC recommended a strategic Federal initiative in long-term information technology R&D and outlined the research priorities that will drive the necessary advances in the new century.

The PITAC subsequently convened a group of panels led by Committee members and including invited outside participants with relevant expertise to examine some of the transforming applications of information technology in greater detail. Three panels focused on information technology national challenges: Transforming Government, Transforming Health Care, and Transforming Learning.

Several other panels examined critical technology issues that span the transformations, including Digital Divide Issues, Digital Libraries, International Issues, and Open Source Software for High End Computing. Over the past year, each of the panels has analyzed relevant research data and documents; held workshop discussions and conducted interviews with experts in their fields; and studied the fiscal, organizational, and economic implications of strategies to generate necessary information technology research and development advances in these key areas of our national life. The Committee plans to convene additional panels in the months ahead.

"Transforming Health Care Through Information Technology" and the other reports in this series present targeted findings and recommendations to the President and Congress designed to help the Nation realize the vision of these positive transformations. Their benefits for our future can be extraordinary, but they are not guaranteed. To make the vision a reality, we need the results of aggressive, well-funded, and well-managed Federal research programs.

Acknowledgements

The Panel on Transforming Health Care benefited from four recent reports that also address information technology and its potential to change health care and biomedical research. These are:

- "Networking Health: Prescriptions for the Internet" by the National Research Council's Computer Science and Telecommunications Board (through its Committee on Enhancing the Internet for Health and Biomedical Applications: Technical Requirements and Implementation Strategies). The study was chaired by Edward (Ted) Shortliffe, the co-chair of this PITAC Panel, and included as members the following Transforming Health Care Panel members: Bruce Davie, William Detmer, and John Glaser. (See http://books.nap.edu/catalog/9750.html)
- The Biomedical Information Science and Technology Initiative report by the Advisory Committee to the Director, NIH Working Group on Biomedical Computing, which was co-chaired by Larry Smarr, a member of the PITAC Transforming Health Care Panel. (See http://www.nih.gov/about/director/060399.htm)
- "Toward a National Health Information Infrastructure," June 2000, National Committee on Vital and Health Statistics Interim Report, which was produced by the Workgroup on National Health Information Infrastructure and chaired by Dr. John Lumpkin. (See http://ncvhs.hhs.gov/NHII2kReport.htm)
- "Highway to Health: Transforming U.S. Health Care in the Information Age," March 1996, Council on Competitiveness. (See http://nii.nist.gov/pubs/coc_hghwy_to_hlth/title_page.html)

The Panel enthusiastically supports the recommendations of all four reports.

The Panel thanks all the Federal managers who provided useful information and guidance for the Panel's deliberations. They included:

- Ruzena Bajcsy, Assistant Director, Directorate for Computer and Information Science, NSF
- Mary Clutter, Assistant Director, BIO/OAD, NSF

- Mike Huerta, Associate Director, Division of Neuroscience and Basic Behavioral Science, National Institute on Mental Health,, NIH
- Mike Marron, Director, Biomedical Technology, National Center for Research Resources, NIH
- Glenn Rogers, Deputy CIO, Food and Drug Administration (FDA)
- Ray Russo, Director, Division of Software Engineering Services, FDA

Centers for Disease Control participants:

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- Dr. Patrick O'Carroll, Medical Officer, Public Health Practice Program Office
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- Jim Scanlon, Director, Division of Data Policy
- Christy Schmidt, Deputy to the DAS of Health Policy

The Panel would also like to acknowledge the work of the National Coordination Office for Information Technology Research and Development in supporting its efforts to produce this report. The Panel thanks Yolanda Comedy and Kay Howell, who coordinated Panel activities and kept us on track toward our final report. We thank Martha Matzke, who edited and formatted the final document. And we are grateful to Cita Furlani, Director, and the entire staff at the National Coordination Office. Our meetings went smoothly because of their careful preparation.

A Vision of Better Health Care Enabled by Information Technology

Telemedicine applications are commonplace. Specialists use videoconferencing and telesensing methods to interview and even to examine patients who may be hundreds of miles away. Computer-aided surgery with Internet-based video is used to demonstrate surgical procedures to others. Powerful high-end systems provide expert advice based on sophisticated analysis of huge amounts of medical information. Patients are empowered in making decisions about their own care through new models of interaction with their physicians and ever-increasing access to biomedical information via digital medical libraries and the Internet. New communications and monitoring technologies support treatment of patients comfortably from their own homes.

Information Technology Research: Investing in Our Future
Report to the President, February 1999
President's Information Technology Advisory Committee

Overview

Information technology offers the potential to expand access to health care significantly, to improve its quality, to reduce its costs, and to transform the conduct of biomedical research. The quality of U.S. health care and medical research are the envy of the world, but U.S. health care costs as a percentage of gross domestic product are among the highest in the world and are increasing despite recent changes in health care organization and financing. Further, a recent report from the Institute of Medicine (IOM), "To Err is Human," points out that despite our favorable reputation for especially complex care management, our health care system is not nearly as safe as it could be. The report argues that significant improvements in care would be possible if modern

clinical information systems were widely implemented and a sound national health information infrastructure were in place.

Other problems plague the U.S. health care system. Forty-five million Americans either have no health insurance or are significantly underinsured. Access to care for many others is limited by geography. Hence, while there is much about U.S. health care to admire, we should recognize that there is much yet to be achieved and that information technology can play a major role in facilitating cost-effective improvements that are necessary. The Government has emphasized, in its Health People 2010 Program, that our goal as a Nation should be to assure a healthy population – this is key to attaining other important national goals such as maintaining a high quality of life, sustaining a sound economy, and ensuring national security.

Historically, research and education have been the cornerstones of American health care. The quality and economic efficiency of medical diagnosis and therapy have been, and continue to be, driven by a continual process of analysis, integration, and dissemination of the results of basic science and clinical research. Advances in information technology (including networking, databases, and computer-based methods for collecting, analyzing, and visualizing the data originating from both individuals and populations), offer unprecedented opportunities for enhancing the quality of research. In turn, they can enhance the efficiency with which new knowledge can be generated, analyzed, and integrated into health care education and delivery.

Advances in information technology can provide the foundation for important improvements in health care delivery, such as more cost-effective monitoring and follow-up of patients beyond health care centers and dynamic, optimal targeting of specific sectors of the population for special education, screening, and early treatment where necessary. Information technology can also help to provide better feedback loops for connecting providers, policymakers, and patients with late-breaking research and discussions about clinical decision-making policy. Only information technology can help us take data from records of individual care and make them available for analysis of populations, both for the generation of new epidemiological knowledge and for the

generation of prudent health policy.

It has long been recognized that clinical care involves major issues in information generation and management. In recent years it has become clear that biology, and hence biomedical research, also offer major information technology opportunities and challenges. The growth of statistical methods, such as double-blind randomized clinical trials, has changed the "rules of evidence" from a reliance on expert opinion to demands for solid evidence with adequate sample size and good study design.

The "new biology" is inherently an information management and analysis challenge, with a huge explosion in the size of datasets ranging from DNA and protein sequences to high-resolution images of cellular components, tissues, organs, and organisms (including human beings). Information technology is thus becoming essential to the biomedical research community, both to manage and analyze data and to model biological processes, giving rise to the field of bioinformatics. Scientists in major research centers are collaborating around the world on the Human Genome Project to build the ultimate genetic "road map." The size and scope of the Human Genome Project demand intensive computing capability. This huge analytical effort also requires a robust communications infrastructure to allow colleagues to exchange information and to access the same databases.

Computer modeling and simulation likewise have become increasingly important to the field of medicine. By applying high end computing to complex problems, biomedical researchers have developed more accurate ways to locate abnormalities where traditional experimentation would be costly, unethical, dangerous, or simply impossible. For example, interactive technologies to steer and make modifications in virtual environments, to control large-scale computations, and to visualize results can aid in precision surgical planning. Such surgical goals require an enhanced level of interaction with high end computing, visualization, and large-scale data computation technologies – all within a time-critical environment.

Use of high end computing for the correlation of large clinical databases with related genetic information may similarly lead us to

important new insights as we attempt to understand the relationships between inheritance, disease development, and varying responses to therapy. Insights from such statistical analyses will help to define further research to assess whether associations discovered in "data mining" are in fact based on causal relationships. Similar analyses regarding clinical care patterns may help to elucidate what factors in our complex adaptive systems for disease management are the most effective. This will in turn provide a foundation for identifying the processes of care that should be embedded in computer-based health records.

Challenges to achieving the vision

The health sector will experience unprecedented change as it begins to take advantage of information technologies to increase productivity and to improve the quality of care. While new technologies can provide great opportunities for improving health care, several challenges exist to realizing the potential benefits to Americans' health and health care. The Panel made the following findings about these challenges:

Finding 1. The U.S. lacks a broadly disseminated and accepted national vision for information technology in health care.

Health care organizations are not well prepared to adopt information technology and applications effectively. Health care is largely a decentralized industry populated by diverse organizations with different motives, resources, and incentives. Fiscal constraints hinder the industry's ability to make major investments in information infrastructure and applications unless these investments can be shown to lead to significant and low-risk returns. Provider organizations lack information about the efficiency of information technology solutions in terms of both cost and quality, making it difficult for them to make decisions about information technology investments. We now have sufficient evidence to state that computer-based patient records can substantially improve patient care, outcomes, and costs. Yet to date we do not have the national commitment to assure that Americans will reap the benefits of this technology.

The National Committee for Vital and Health Statistics (NCVHS) and the Data Council of the Department of Health and Human Services (DHHS) do have a template vision for a national health information infrastructure. Visions promulgated by committees, however, need focussed leadership from within the Department and/or the White House to develop the program and budgets to make that vision viable.

Finding 2. Critical, long-term research, technology, and policy issues need to be addressed if we are to realize the potential of information technology to improve the practice of health care.

While significant advances in information technology have been achieved, many hard problems remain. For example, user interfaces that are easier to use and more easily integrated into the ergonomic patterns of health care can catalyze greater acceptance and use of innovative computer-based tools in medicine. Robotics and remote visualization methods supported by high-reliability and low-latency communications are needed to enable applications such as telepresence surgery. Reliability of systems and software is critical for many health care applications. Human life may be at risk if information sent to medical monitoring or dosage equipment is corrupted or degraded, or if electronic medical records cannot be accessed in a timely, reliable way.

Knowledge repositories are an important research topic, including techniques for integrating data from multiple sources. Stronger forms of authentication are needed, both for persons accessing data and for assuring the integrity of the information. Methods are needed to protect patients' privacy while allowing valuable medical research and necessary reimbursement tasks to be performed. In providing health care, doctors need to collaborate with researchers, with public-health specialists, and with the people who manage patient billing. Each of these people, and many others, need access to part of the patient's medical record, but not necessarily to the entire record. Better access-control methods would make it possible to partition and isolate the data elements as needed to protect patient privacy. Improvements in computational capability are therefore essential, including faster processing and more networked resources to meet the increased demands of modeling complex systems

and performing information retrieval, data analysis, and automated inferencing.

From a policy perspective, perhaps the most significant problem is the lack of reimbursement for a range of applications that have demonstrated value, e.g., telemedicine, patient-provider interactions over the Internet, efforts to reduce medical errors, and initiatives that link a patient's data across provider organizations. Further complicating matters is the fact that health care providers are currently licensed by individual states and are generally prohibited from providing care across state lines. This becomes a clear issue when a patient is in one state but the physician at the other end of a telemedicine link is in another. Liability claims are also handled at the state level, with considerable variation among states.

Finding 3. The introduction of integrated decision-support systems that can proactively foster best practices requires enhanced information-technology methods and tools.

Decision-support tools can provide critical links between a current patient's condition and previous clinical studies. Existing systems largely focus on detecting errors at the source, through such methods as range checking, alerts, and reminders, or post-hoc quality monitoring and review. While these types of systems are vital components for improving quality of care, important information is often unavailable or inaccessible because it is spread across multiple information systems and/or organizations with differing systems. This can result in poor coordination of care and increased illness and mortality. The challenge of going beyond these approaches to ones that proactively foster best practices will require efforts in the following areas:

- Expanding the range and granularity of routinely captured data
- Standardizing terminology
- Developing robust techniques for incorporating new data types into existing clinical data repositories, e.g., images and patient genotype

- Organizing and collecting large-scale databases to determine best practices
- Developing guidelines based on such evidence
- Implementing guidelines so that they are usable effectively at the point of care, including embedded decision support that is continually updated as new evidence accumulates.
- Reducing the cost and difficulty of integrating applications that reside on heterogeneous technologies

Finding 4. **Achieving the potential of information technology to improve health care will be constrained until we develop a larger cadre of researchers and practitioners who operate at the nexus of health and computing/communications.**

The United States lacks a widely accepted vision for the creation and use of information technology tools to increase effectiveness in our health care system. In part, this is due to a lack of critical investment by the biomedical community in computer infrastructure and enabling technologies. This issue becomes increasingly difficult to solve because the number of individuals who understand both the health care milieu and information technology is remarkably small. Yet, if DHHS is to accomplish its mission to improve the quality of health care in the U.S., an increase in biomedical information technology expertise is a critical need.

Finding 5. **The biomedical community, including the Federal research agencies, has tended to rely on information technology innovations that are produced by investments in other parts of Government.**

The quality of U.S. health care is increasingly dependent on the effective use of new and emerging information technologies. Yet Federal health agencies have played a limited role in supporting research and development in computer science. Unfortunately, the health care and biomedical research communities have generally viewed information

technology as a tool to enable health care applications and support biomedical research, rather than a critical research field. DHHS has heavily leveraged information technology research and development investments made by other Federal agencies such as the Defense Advanced Research Projects Agency (DARPA), the Department of Energy (DOE), the National Science Foundation (NSF), and the National Aeronautics and Space Administration (NASA). While DARPA, DOE, NASA and other Federal agencies consistently make significant investments in fundamental information technology research and development, their primary mission is not health care and therefore their priorities do not necessarily match the critical needs of health care research and education.

DHHS has failed to make vital investments in fundamental information technology research and development and, as a result, health care lags behind other sectors. If DHHS does not begin to make substantial investments in information technology research and development, two serious problems will arise. First, the pace at which biomedicine benefits from information technology research will be adversely affected. Second, the needs of the biomedical community will not be reflected in the priorities of the other Federal agencies unless the biomedical community itself is involved in information technology research. Similarly, the biomedical research agencies must collaborate on an equal footing with the other Federal research agencies that have dominated information technology research in the past.

Finding 6. The role and management of information technology in the Department of Health and Human Services has several limitations, which must be addressed if the health care community is to benefit from the promise of the information age.

DHHS does not have a clear, strategic vision of the benefit that the department and all of its agencies could receive from information technology research and use of information technology tools. It is evident that the decentralized management approach of DHHS has adversely affected both the development of a coherent information technology vision and the influence of departmental activities regarding

information technology and its role in health care and biomedical research. It is important to change this practice and ensure that DHHS has the necessary leadership and budget and a coordinated information technology effort across all its agencies. In our discussions with DHHS agencies, it became clear that they do not have a mandate or budget to support information technology research, even though it is fundamental to their mission.

Although the Administration and Congress have placed a high level of confidence in information technology's benefit to this country, DHHS is not perceived as a significant player in Federal information technology research or policy development. It is clear, however, that state-of-the-art research advances in any field require state-of-the-art investments aimed at solving problems, developing the technology, and building the right infrastructure.

Recommendations

Recommendation 1. Establish pilot projects and Enabling Technology Centers to extend practical uses of information technology to health care systems and biomedical research.

The Government has an enormous opportunity to advance the technological capability of U.S. health care by funding pilot projects and large demonstration programs to explore the application of emerging information technologies to health care systems and biomedical research. Few health care organizations have strong incentives to implement such systems on their own, given the uncertainties surrounding the effectiveness of new technologies in health care, the scale at which such systems may need to be built, and the paucity of highly skilled information technology professionals needed to implement such systems.

One excellent current research program, the Federal Next Generation Internet (NGI) Initiative, aims to provide additional services and capabilities that could enhance the Internet's ability to support the

needs of the health sector. The NGI will also make available network testbeds for evaluation of health applications on the Internet and their requirements. The networks being deployed by the NGI can support a range of experimental health applications, such as remote medical consultations, collaborations among researchers and health practitioners, and access to online repositories of information. DHHS is involved with the NGI through the National Library of Medicine (NLM), which has awarded several contracts to investigate and develop health care applications utilizing NGI services and capabilities. NLM's participation provides a critical link with the networking community to help ensure that it understands the needs of the health community.

Additional Federal funding would play an important role in stimulating necessary research, especially if the funding is focused on applications that link multiple organizations. In addition to focusing on applied technology and development for the specified application area, Enabling Technology Centers could make significant contributions to addressing workforce issues. For example, researchers at the centers could develop educational programs and curricula to bridge the intersections among computer science, engineering, and the application domain. The centers could also help build communities of researchers, health care practitioners, Federal health care officials, industry, and other stakeholders by convening workshops and conferences, and publishing case studies of successful and unsuccessful uses of information technology.

Examples of recommended projects include:

- Simulation of the human body, from "molecular first principles," to build a complete structural and physiological model of the human body at many levels between molecular and whole organism (e.g., organelle and cell assembly, tissues, organs), linking structure to functions and processes when known, focusing on common diseases in a continuum from molecular changes to visible clinical manifestations.

- Remote-care applications that integrate sensor technologies and/or remote instrumentation to monitor patients. For example, a significant number of people who reside in nursing homes are

there more for health "security" reasons than for heath care "needs." Many residents in extended-care facilities could be cared for at home at significantly reduced costs if the appropriate telemedicine tools were available to enable remote monitoring. Additionally, many of the home-health visits conducted today are based on the need to observe or monitor a patient's status, a function that could be accomplished through interactive video systems coupled with the appropriate instrumentation and a simple-to-use interface.

- New delivery modes for educating medical practitioners and providing continuing medical education. Examples include distance-learning projects, whereby students can attend grand rounds in different hospitals or lectures by experts not available at their home campus, could permit practitioners to supervise students in distant locales.

Recommendation 2. **NIH, in close collaboration with NSF, DARPA, and DOE, should design and deploy a scalable national computing and information infrastructure to support the biomedical research community. This infrastructure should include an aggressive biomedical computing capability similar to that of DOE's Accelerated Strategic Computing Initiative (ASCI) program.**

Computational-biology and other biomedical problems require the fastest computing cycles and information processing capabilities achievable today. And as we seek to improve our knowledge of the human body, these computing requirements will grow exponentially. There should be a biomedical equivalent of DOE's ASCI that seeks to provide multi-teraops/teraflops computing capability to high-end users and to fund the development of improved algorithms and enabling technologies for terascale systems. Facilities with mid-level computers also should be made available for researchers to test and develop code before moving to large systems. These mid-level systems can also be used for developing new algorithms and applications for biological problems.

To enable this distributed, scalable computing environment, investments are needed in software to support grid technologies to

permit dynamic allocation of computing and information processing capability as needed. Long-term information storage and management of biomedical databases are also important computing infrastructure requirements. DHHS should work with the community to decide which databases are to be maintained, for how long, and by whom. DHHS also should provide the necessary funding to support the infrastructure needed to maintain the databases over the long term.

Recommendation 3. **Congress should enhance existing privacy rules by enacting legislation that assures sound practices for managing personally identifiable health information of any kind.**

Protections are needed that deal with unauthorized access and disclosure and that allow for appropriate access and amendment by patients. Governing the stewardship of and access to medical information is an important issue. Legislation should identify the national standards by which information can be shared, should permit electronic authentication of information, and should include sanctions/penalties for violations. Despite the recent announcement of privacy regulations in response to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), uncertainties can be dealt with convincingly only by a clear legislative mandate.

Recommendation 4. **Establish programs to increase the pool of biomedical research and health care professionals with training at the intersection of health and information technology.**

The Panel applauds the efforts of the NIH 's Biomedical Information Science and Technology Initiative to establish National Programs of Excellence in Biomedical Computing to support learning at the interfaces among biology, mathematics, and computation*. Such programs can play a significant role in educating biomedical-computation researchers. DHHS should identify and nurture similar programs to provide training at the intersection of information technology and health care professionals. For new applications of

* See http://www.nih.gov/about/director/060399.htm.

information technology to health care to be envisioned, developed, and implemented, it will be necessary to build teams of health care application experts, biomedical researchers, and computer scientists. Such teams can build bridges among near-, mid-, and long-term R&D to ensure rapid adoption of new technologies in the health care system. DHHS should explore other educational opportunities, such as expanding health informatics training programs and curricula within the schools of health professions and computer science departments.

Recommendation 5. DHHS should outline its vision for using information technology to improve health care in this country and subsequently devote the necessary resources to do the basic information technology research critical to accomplishing these goals in the long term.

DHHS should develop an agenda to remove the policy barriers that currently inhibit the use of information technology in support of health care. This might, for example, include the development of an expanded agenda at the Health Care Financing Administration (HCFA) to evaluate the impact of such technologies on care quality and costs and to provide reimbursement (or other incentives) should the impact prove to be socially valuable.

The Department should also establish an aggressive research program in computer science that is motivated by health needs. It is important that the research program address long-term needs, rather than the application of existing information technology to biomedical problems. Some entities within DHHS, most notably NLM but also other elements of NIH and AHRQ, have invested in research in applications of computing and communications technologies. But much of this work has had short-term goals and DHHS itself has not made information technology research and development in health- related activities a priority. Financially stressed health care organizations will not increase their commitment to the use of information technology without strong leadership and demonstrations of value.

The health community must articulate its needs to the information technology research community and must actively engage in developing

information technology solutions. DHHS should play a lead role in doing this. The goals should be to assure that funding agencies and researchers better understand the ways in which the requirements of health care applications diverge from, or converge with, those innovations needed to support requirements in other sectors, and to ensure adequate support for biomedically motivated fundamental research in computer science to address those needs. Illustrative information technology R&D topics important to health care include:

- *Information management* to enable automated analysis of primary data; meta-analysis across studies; and automated understanding, indexing, and content retrieval based on combinations of text, audio, images, motion, and context. Also pertinent are methodologies for "automated policy inference" that integrate data from diverse sources (e.g., epidemiologic, economic, demographic, geographic), and models of societal resources and values to suggest plausible public health responses to major health problems.

- Automated *tailoring of information access and summaries* to accommodate variations in culture, language, literacy, health-related goals, and reliability of information. Such capabilities are motivated by the need for seamless access to patient-specific and general medical information at the point of care, specifically when relevant to an individual's immediate care and when context-sensitive to a provider's prior knowledge and history of prior system use.

- Research on *user-interface hardware and software* to promote the development of better solutions to the problem of human-computer interaction in health care. Advances are needed in embedded intelligent agents, hands-free computing environments, natural language processing, speech understanding, handwriting recognition, and notepad inputting schemes.*

* This recommendation was also made in the Council On Competitiveness report, "Highway to Health: Transforming U.S. Health Care in the Information Age", March 1996, http://nii.nist.gov/pubs/coc_hghwy_to_hlth/chp5.html.

- *Multimodal information management* of clinical images to support automated indexing ("image digests") using both image processing, with power sufficient to retrieve "look alikes" without human-assigned textual tags, and also biostructural 4-D indexing (3-D + change over time). Examples would include automated indexing and retrieval of videos showing gait dysfunction and neurologic syndromes; language understanding to support automated indexing of full text to permit document retrieval with high precision and recall; and techniques to recognize and generate spoken language to support indexing, capture, use, and retrieval of voice input.

- Research in advanced networking services including: techniques for assuring *quality of service* across the Internet to assure that information will be delivered to its destination quickly and accurately; *multicast capability* to make more efficient use of available bandwidth to distribute information simultaneously from one user to a number of specific recipients; symmetric or dynamically reconfigurable broadband technologies for the "last mile" (i.e., connections between the Internet and homes or offices); and *wireless technologies* to support untethered access to computers and information.

- Development and availability of *high-end systems* to support modeling of biological processes and both management and analysis of data. Implied components include research in middleware, algorithms, data management, and visualization of large data sets to enable efficient use of such high-end systems.

- *Privacy, security, and authentication* to ensure that information is available to those who need it, protected against those lacking proper credentials, and not modified, either intentionally or unintentionally, in violation of established policies and procedures.

- Research to help us better understand the *ethical implications of information technology on the health care system.* For example, vendors, health care delivery organizations, and payers will need

to consider the cultural, economic, and generational diversity of the population when developing health and wellness information products and services. Issues to consider include the technical literacy of the targeted population as well as its access to certain information-delivery tools in order to select appropriate means and formats of communication.

Recommendation 6. **DHHS should appoint a senior information technology leader to provide strategic leadership across DHHS and focus on the importance of information technology in addressing pressing problems in health care.**

Information technology is of critical importance to the Nation and can be instrumental in providing the best possible health care to all of our citizens. At this time, information technology research and use are not viewed within DHHS as strategically as is necessary. We therefore recommend that DHHS create a high-level position designed to provide the necessary vision for the agency in its efforts to incorporate information technology in its agency mission and strategy. While we cannot best judge how this should be accomplished, we recommend that the position be at least at a level equivalent to the deputy undersecretary. This person should be an expert who operates at the nexus of health and computing/ communications. In addition, a budget should be provided to facilitate this person's coordinating and educational activities.

Summary

New information technologies have the potential to dramatically improve our health care system as it exists today. Information technology can help ensure that health-related information and services are available anytime and anywhere, permit health care practitioners to access patient information wherever it may be located, and help researchers better understand the human body, share information, and ultimately develop more beneficial treatments to keep Americans healthy. Implementing the recommendations made in this report would represent a major step toward realizing the potential of information technology to increase every American's access to quality health care and to decrease the cost of health care delivery. The Federal government has a unique role to play in supporting research in this critical area and in coordinating its own cross-agency activities in the application of information technology to health care.

Publications of The President's Information Technology Advisory Committee

Information Technology Research: Investing in Our Future, February 1999, 80 pages.

Resolving the Digital Divide: Information, Access, and Opportunity, February 2000, 24 pages.

Transforming Access to Government Through Information Technology, September 2000, 32 pages.

Developing Open Source Software To Advance High End Computing, October 2000, 28 pages.

Transforming Health Care Through Information Technology, February 2001, 32 pages.

Using Information Technology To Transform the Way We Learn, February 2001, 48 pages.

Digital Libraries: Universal Access to Human Knowledge, February 2001, 32 pages.

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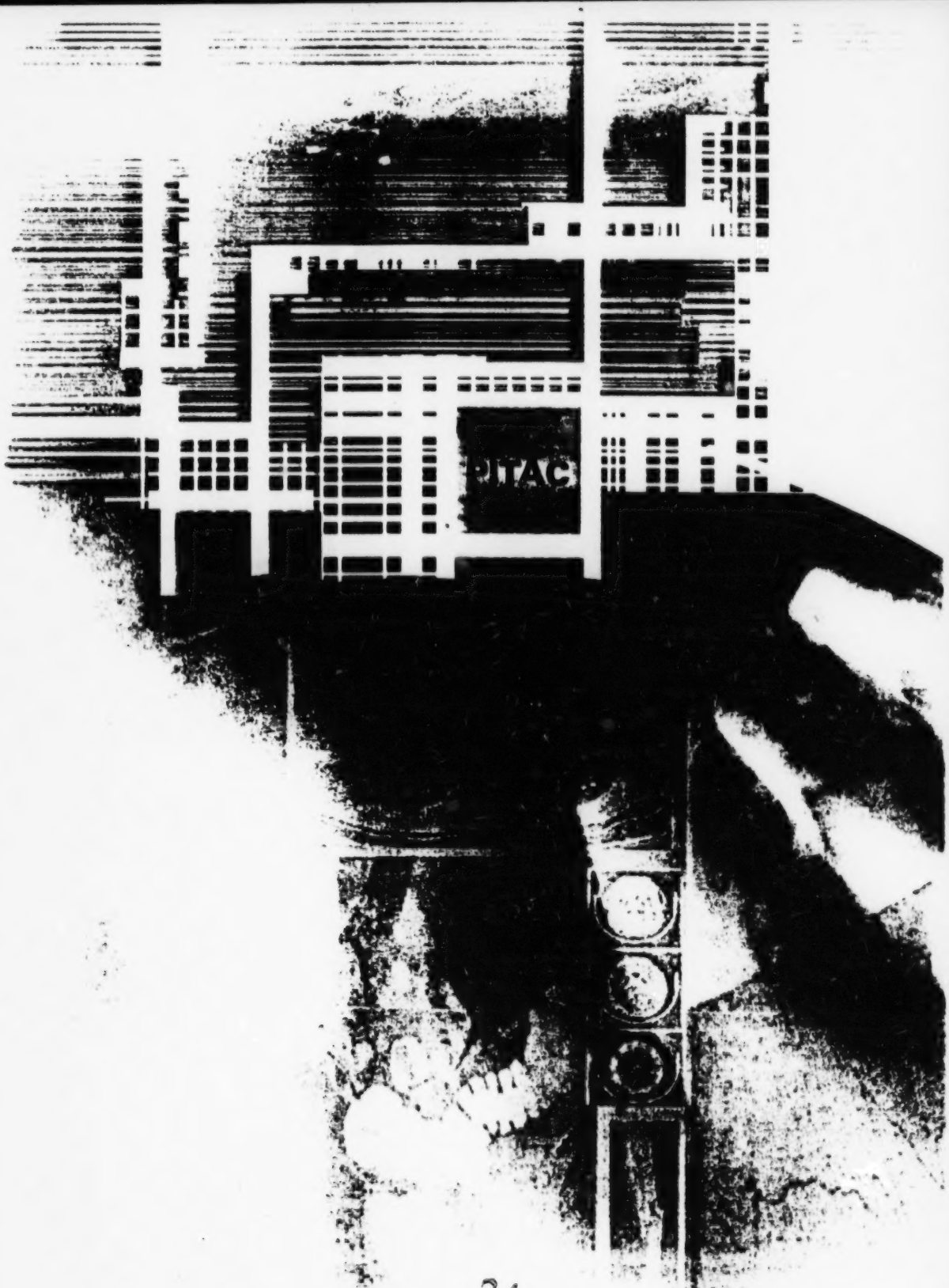

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